

# Standards of Care in Epilepsy

Current Access to Basic Epilepsy Care Across the  
European Union

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# Summary

- Epilepsy can be complex, but is (always) treatable
- There is a “treatment gap” in epilepsy
  - Not just in the “developing world”
- There is within-country variation in the standard of care delivered to patients with epilepsy
- There is variation across the EU in the type of epilepsy care delivered to its citizens
- Need (ongoing) action on published reports

# Epilepsy

- A group of (many) neurological disorders characterised by the tendency to have recurrent unprovoked seizures
- Every patient's epilepsy is unique
- Common, across the age spectrum
- Over one third have difficult to control epilepsy
- “Epilepsy and related disorders”
- Six million in Europe (+)

# Epilepsy Standards

- Reports / guidelines / declarations
  - European White Paper on Epilepsy, 2001
  - NICE / SIGN, 2004
  - European Declaration on Epilepsy, 2011
  - National Audit of Seizure Management in Hospitals (NASH), 2012
- Many recommendations
- Some progress
- But slow....
- Why are we here?.... Why we are here?.....

# European White Paper on Epilepsy - Call to Action 2003

We call upon the intergovernmental bodies and institutions in Europe, and individual Member States, to implement and support the following three actions:

- Improve public understanding of epilepsy via educational programmes throughout Europe to raise awareness and reduce stigmatisation of patients
- Provide legislation to protect people with epilepsy from discrimination in the workplace to ensure equal job opportunities and thereby reduce the socio-economic burden of the condition
- Increase investment in research in epilepsy in order to improve the diagnosis and treatment of epilepsy throughout Europe

# An Individual with Epilepsy Deserves

- Timely competent assessment
- A correct diagnosis
- Appropriate safe treatment
- Regular appropriate follow up
- No seizures
- No side effects
- No co-morbidity
- Availability of a patient support group
- An opportunity to participate in clinical research

# What is a Standard?

- An approved model
- An average or normal requirement
- An accepted or approved example of something against which others are judged or measured
- *A level of excellence or quality*

# Quality Care in Epilepsy

- Timely
- Appropriate
- Access to EEG and MRI
- Referral to other specialties when needed
- Video EEG monitoring (invaluable resource)
- Epilepsy surgery
- Chronic disease care

# Chronic Disease Management Recommendations

## **Self-management:**

*Knowledgeable patient*

*Active patient participation in partnership with healthcare practitioners*

*Improve compliance & adopt healthier life-styles*

## **Integrated care:**

*Improve continuity & co-ordination of care*

*Multi-professional collaboration*

*Primary & specialist care partnership*

*Role expansion e.g. nurse specialists*

## **Clinical guidelines:**

*Evidence based treatment & care*

*Enhance quality & safety*

*Improve consistency of care*

*More efficient use of healthcare resources*

## **Clinical information systems:**

*Timely sharing & exchange of clinical information*

*Web-based electronic patient records*

*Health service monitoring, evaluation & planning*

# AAN Epilepsy Quality Measures in Clinical Practice - Each Visit

- Seizure type and current seizure frequency
- Epilepsy syndrome and aetiology of epilepsy
- EEG results
- MRI results
- Querying and counselling about AED side effects
- Referral for surgical treatment when appropriate
- Counselling about specific safety issues
- Counselling about contraception and pregnancy
  - Fountain N et al, Neurology 2011.

# The Patient Health Care Journey

- A rocky road..... - Irish example
- One to one interviews with patients
  - Delayed access to specialist epilepsy review
  - Uncertainty regarding the competency and function of primary care services
  - Significant unmet needs for female patients with epilepsy
  - Disorganisation of existing epilepsy services
  - Unmet patient information needs
    - Varley J et al, Epilepsy and Behaviour, 2010

“being honest you know we had to wait 18 months for this appointment, it’s an awful long wait in case anything would happen to him.”

“....I changed doctor and he classed me as severe when he saw me..... and the other doctor kept giving me medication and not sending me nowhere.”

“went to my GP and I said what drugs should I be on...is this proper?... And they were like, yeah, as long as you’re on the folic acid and you’re on the medication with your folic acid.”

“there was definitely a gap there....like different hospitals were doing different things.”

“annoyance with lack of communication between the hospitals... a specific EPR available via the internet a way to improve bad management”

# National Programme in Epilepsy

- Establishment of **Network of Regional Epilepsy Centres** 4 adult, 2 paediatric (Done)
- Population-based **nurse-led ambulatory service**. (17 of 27 nurses in place so far). 4 awaiting contracts to be signed and 6 to be interviewed).
- **Integrated care pathway** for acute hospital based seizure management.
- **45 SOPs developed** for all aspects of the service delivery. 12 in use routinely
- **Expanded pre-surgical evaluation** programme in 2 centres (unit completed in CUH and under construction in Beaumont - 10 nurses to be appointed to each)
- Nationwide **electronic patient record** access for community outreach
- Links to Epilepsy Ireland and other informational resources for self-management.
- 24 - 7 countrywide telephone advice for health professionals (after units open)

(Colin Doherty)

# Who Delivers this Care?

- General Practice
- Consultant Physician
- Consultant neurologist / epileptologist and team
  - Neurophysiologist
  - Advanced nurse practitioners
  - Community epilepsy nurse
  - Clinical nurse specialist
  - Non-consultant hospital doctors
- Psychiatry (especially LD patients)
- Paediatrics
- A multi-disciplinary team

# Care in Europe

- Commission on European Affairs; Appropriate Standards of Epilepsy Care Across Europe
  - Brodie M et al, Epilepsia, 1997
  - An outline of appropriate care throughout Europe
- The Provision of Epilepsy Care Across Europe
  - Malmgren et al, Epilepsia, 2003
- Current Status of Epilepsy Health Care for Adult Patients from Central and Eastern European Union - A Survey of Members of the Central Europe Epilepsy Experts Working Group
  - Jedtzejczak J et al, Seizure 2013 (In Press)

# Numbers of Population Per Neurologist

|           |                     |
|-----------|---------------------|
| Australia | 51,900              |
| Belgium   | 71,000              |
| Finland   | 20,200              |
| France    | 39,300              |
| Germany   | 41,100              |
| Greece    | 21,200              |
| Iceland   | 15,500              |
| Ireland   | 300,000 – (120,000) |
| Japan     | 63,000              |
| Holland   | 25,100              |
| Sweden    | 30,500              |
| UK        | 164,000 – (120,000) |
| USA       | 26,200              |

# Epilepsy Care Across Europe 2003

- Survey of 36 European Chapters (89% response rate)
  - European Epilepsy Services Inventory (EESI)
- Wide range in the number of physicians and specialists involved in epilepsy care across Europe
- Problems with high cost of AEDs in eastern Europe
- Stigma and social problems
- Insufficient education and knowledge about epilepsy commonly reported
- Surgery may be underused, even when available
  - Malmgren et al, 2003.

# Epilepsy Care in Central and Eastern Europe

- Survey of experts in ten countries
  - Bulgaria, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Romania, Slovakia, and Slovenia
- Number of neurologists and specialist epilepsy centres highly variable
  - Seven countries have epilepsy surgery centres
  - Latvia, Slovakia, and Slovenia refer abroad
  - Very variable waiting times
  - 20% of epilepsy patients in Latvia treated by a psychiatrist
- Re-imburement systems for AEDs highly variable, with some limitation on prescribing for particular AEDs in some countries
  - Jedtzejczak J et al, Seizure 2013 (In Press)

# The Continuing Bottom Line...

- “the lack of unified procedures pertaining to the evaluation and therapy of epilepsy is reflected by marked differences in access to treatment modalities by patients”
- “It is clear that the co-ordination of services is often inadequate and resources are not being used efficiently”
- “Lack of comprehensive care, stigmatisation, and social problems such as unemployment were reported all over Europe”

# What Is / Needs to be Done?

- Educate, educate, educate
- Basic standards of care across Europe
  - Role of CEA
- National Centres for Complex Epilepsy - across Europe
- Develop and use ICT / EPRs
- Funding for Research
- Co-operation / collaboration

# Preparing for the Future

- Common epilepsy is likely to be a collection of individually rare molecular disorders
- Ongoing European research efforts
  - E.g., E-PILEPSY
- ICT - implementation of epilepsy EPRs
- The explosion of new genomics
- Whole exome / genome sequencing
  - Understanding causation
  - Improving individualised therapies
  - Challenges of “big genomic data”

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